

FIGHT ALZHEIMER'S
SAVE AUSTRALIA
FIGHTDEMENTIA.ORG.AU

**SUBMISSION TO THE PRODUCTIVITY
COMMISSION ISSUES PAPER**

DATA AVAILABILITY AND USE

JULY 2016

EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the opportunity to respond to the Productivity Commission's April 2016 Issues Paper, *Data Availability and Use*.

Our response is based on the premise that high quality, relevant data must be available to inform policy and service planning in Australia in relation to people with dementia and their carers. With the ageing of the Australian population, the care and support of people with dementia is one of the largest healthcare challenges facing Australia, and the challenge is growing. It is critical moving forward that we have good data on prevalence and burden of disease, on risk factors and protective factors, on diagnosis and treatment, and on service supply and demand.

There are significant gaps and limitations in current data collections in relation to dementia prevalence, which need to be addressed. Continued resourcing for collation and analysis of data on dementia and service use is required. Effort is also needed to improve data collection and analysis in relation to people with dementia in the aged care system, to inform service planning; and better data on quality in aged care is needed to assist consumers to make informed choices. Finally, appropriate access to data for research purposes is required.

RECOMMENDATIONS

1. The options put forward by the Australian Institute of Health and Welfare (AIHW) to develop improved dementia data in Australia, beginning with the Australian Government exploring with all jurisdictions how more robust prevalence estimates might be obtained, including through the use of existing data sources and/or the creation of new ones such as a multi-stage population survey along with a dementia registry¹, should be considered for implementation.
2. The AIHW should be resourced to continue to focus on the improvement of data and the development of better information about dementia prevalence and service use by people with dementia, to ensure there is an adequate evidence base on which to build policy and programs to address this increasingly significant health priority.
3. The options put forward by the AIHW for improving data consistency and quality in the aged care system, including looking for opportunities in the current aged care reform process to incorporate a focus on improving dementia data in routine aged care data collections,² should be considered for implementation.
4. Data on performance and quality of aged care services should be routinely collected, analysed, and made publicly available, to assist consumers in making informed choices in regard to the services they receive. The public availability of such data will also help to drive service competition and quality improvement.
5. Researchers should have appropriate access to public data sets in cases where research and analysis of this data could promote better understanding and knowledge to support efforts to tackle dementia.

¹ Australian Institute of Health and Welfare (2014). *Improving Dementia Data in Australia: Supplement to Dementia in Australia 2012*. AIHW, Canberra, Cat No AGE 76; p.18

² Australian Institute of Health and Welfare (2014). *Improving Dementia Data in Australia: Supplement to Dementia in Australia 2012*. AIHW, Canberra, Cat No AGE 76; pp 20-22.

KEY ISSUES

The importance of data in informing policy and service planning with respect to dementia in Australia

The Productivity Commission Issues Paper notes there has been a recurring suggestion “that governments should substantially improve their own service provision by using data to strengthen the evidence base for their policies and to improve regulatory implementation and enforcement”.³

Alzheimer’s Australia strongly supports the principle of improved use of data to support better policy and service planning in relation to dementia in Australia.

With the ageing of the Australian population, the care and support of people with dementia is one of the largest healthcare challenges facing Australia, and the challenge is growing. It is estimated that there are now more than 353,800 Australians living with dementia and that without a medical breakthrough, this number will increase to nearly 900,000 by 2050.⁴

While the onset of dementia is correlated with advancing age, the condition also affects some younger people. An estimated 25,100 Australians with dementia are under the age of 65. This number is expected to increase to 36,800 by 2050⁵.

Dementia has an enormous impact on the health and aged care system, with the cost of dementia to these sectors calculated to be at least \$4.9 billion per annum⁶. Dementia also has a profound social impact. People with dementia experience stigma and social isolation⁷, and family carers often find it difficult to balance work, life and caring responsibilities⁸.

It is critical that we have an evidence base that helps us to better understand trends in dementia prevalence and burden of disease; the impact of risk factors and protective factors for dementia; the effectiveness of diagnostic techniques; the effectiveness of treatments; and what services are needed for people with dementia, their families and carers, where these services should be located, and how effective these services are⁹. This is particularly appropriate given that since 2012, dementia has been designated as a National Health Priority Area (NHPA). As the Australian Institute of Health and Welfare (AIHW) has stated:

“Designation of dementia as an NHPA brings with it an expectation that there will be ongoing monitoring of changes in the burden of disease arising from dementia. A robust monitoring system would include reporting in relation to prevalence and incidence, changes in the population profile, risk and protective factors, trends in the effectiveness of treatment and care regimes and in outcomes relating to disability, mortality and quality of life.”¹⁰

³ Productivity Commission (April 2016). *Issues paper: Data availability and use*; p.5.

⁴ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁵ Australian Institute of Health and Welfare (2012). *Dementia in Australia*.

⁶ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁷ Alzheimer’s Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

⁸ Brooks D, Ross C, Beattie E, *Caring for Someone with Dementia: the economic, social and health impacts of caring and evidence-based support for carers*. (2015) Report for Alzheimer’s Australia.

⁹ Australian Institute of Health and Welfare (2014). *Improving Dementia Data in Australia: Supplement to Dementia in Australia 2012*. AIHW, Canberra, Cat No AGE 76; p.1. Accessed 5 July 2016 at: <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129548887>

¹⁰ Australian Institute of Health and Welfare (2014). *Improving Dementia Data in Australia: Supplement to Dementia in Australia 2012*. AIHW, Canberra, Cat No AGE 76; p.23.

The need for better data on dementia prevalence

Australia lacks national epidemiological data that could be used to derive more reliable estimates about the number of people with dementia. While the AIHW has invested significant effort in the development of dementia prevalence estimates and in exploring service use, carer issues, expenditure, and related issues¹¹, there are significant gaps and limitations in the data. Improved data about the prevalence of dementia is essential to better inform dementia policy and service planning.¹²

The AIHW has put forward a number of options to develop improved dementia data in Australia, beginning with the Australian Government exploring with all jurisdictions how more robust prevalence estimates might be obtained, including through the use of existing data sources and/or the creation of new ones such as a multi-stage population survey (in which participants are systematically assessed for dementia using both screening tools and clinical diagnostic assessments), and a dementia registry.¹³ Alzheimer's Australia supports this recommendation.

The need for continued resourcing for and focus on data analysis in relation to dementia

While there have been a number of analyses of dementia and related issues in Australia over the years, the Australian Institute of Health and Welfare has been at the forefront of processing data on dementia and presenting it in context – that is, in turning data into information and giving it meaning. In addition to broader studies relevant to older Australians, key recent publications from the AIHW which are dementia-specific have included:

- *Improving dementia data in Australia: Supplement to Dementia in Australia 2012* (2014)
- *Dementia care in hospitals: Costs and strategies* (2013)
- *Dementia in Australia* (2012)
- *Dementia among care residents: First information from the Aged Care Funding Instrument* (2011)
- *Dementia and the take-up of residential respite care: An analysis using the PIAC cohort* (2010)

Such analysis is essential going forward. Alzheimer's Australia strongly recommends that the AIHW is resourced to continue to focus on the improvement of data and the development of better information about dementia prevalence and service use by people with dementia, to ensure there is an adequate evidence base on which to build policy and programs to address this increasingly significant health priority.

¹¹ Australian Institute of Health and Welfare (2012). *Dementia in Australia*.

¹² Australian Institute of Health and Welfare (2014). *Improving Dementia Data in Australia: Supplement to Dementia in Australia 2012*. AIHW, Canberra, Cat No AGE 76; p.

¹³ Australian Institute of Health and Welfare (2014). *Improving Dementia Data in Australia: Supplement to Dementia in Australia 2012*. AIHW, Canberra, Cat No AGE 76; p.18

The need for better data on people with dementia in the aged care system

The AIHW has noted the importance of better identification of people with dementia in aged care data collections, given that the aged care system is a significant provider of services to people with dementia. The AIHW notes that a substantial amount of information on people with dementia is collected in the aged care system, but there is considerable inconsistency in the type of data collected and the definitions used.¹⁴

The way dementia is recorded in the aged care and health sectors needs to be standardised. The way dementia is currently captured and recorded varies greatly, which makes the data much harder to standardise or convert into meaningful information. Transparency about datasets is also important, particularly in relation to service planning and policy development.

The AIHW has proposed a number of options for improving data consistency and quality in the aged care system, including looking for opportunities in the current aged care reform process to incorporate a focus on improving dementia data in routine aged care data collections.¹⁵ Alzheimer's Australia supports this recommendation.

The need for better data for consumers about service quality in the aged care system

The Productivity Commission's Issues Paper notes that some of the potential benefits of increasing data availability and use include empowerment of consumers, as increased access to the data created through everyday transactions can support consumers to make decisions based on what best suits their situation, and provision of data on the relative offerings and performance of product and service providers can help consumers to assess what is available; as well as competition, as wider availability of data can create market opportunities for new businesses, or enable existing businesses to expand into new areas.¹⁶

The availability of better data for consumers on service performance and quality in the aged care system would support both consumer empowerment, and competition and quality within the aged care sector. The aged care system is undergoing a significant reform process, including a move to consumer-directed care, which gives consumers more choice in the services they receive. However, this will only be effective if consumers and carers have access to adequate information including information about service performance and quality, to enable them to engage in informed decision-making.

A voluntary quality-indicator program has commenced within the aged care sector. The program is in the very early stages with data not yet being publically available. The initial indicators included as part of this program are clinically focused and feedback from consumers indicates that there is a need for publically available indicators that capture consumer experience and quality of life within aged care services.

¹⁴ Australian Institute of Health and Welfare (2014). *Improving Dementia Data in Australia: Supplement to Dementia in Australia 2012*. AIHW, Canberra, Cat No AGE 76; p.20.

¹⁵ Australian Institute of Health and Welfare (2014). *Improving Dementia Data in Australia: Supplement to Dementia in Australia 2012*. AIHW, Canberra, Cat No AGE 76; pp 20-22.

¹⁶ Productivity Commission (April 2016). *Issues paper: Data availability and use*; p.9.

Alzheimer's Australia recommends that data on performance and quality of aged care services be routinely collected, analysed, and made publicly available, to assist consumers in making informed choices in regard to the services they receive. The public availability of such data will also help to drive service competition and quality improvement.

Case study on data quality and consistency: DSS Benchmarking under the Data Exchange Framework

Alzheimer's Australia provided a submission earlier this year to the *Benchmarking under the Data Exchange Framework Discussion Paper* issued by the Department of Social Services. Alzheimer's Australia welcomed the intention to use benchmarking data to help foster community awareness and innovation to improve wellbeing for individuals, families and their communities. However, we noted that the value of benchmarking in achieving this aim, and in supporting quality improvement of services, will only be achieved if outcomes reporting is informed by the outcomes experienced by consumers, and if there is integrity to this data. Alzheimer's Australia expressed concern relating to the data collected around consumer satisfaction and consumer outcomes under the DSS proposals, which would allow data collection using a tool of the provider's choice, and a method of the provider's choice. Fundamentally this compromises the comparison value of the data in any benchmarking exercise. Additionally, acceptable sample sizes set very low targets for data that is intended to capture an authentic picture of the consumer outcomes that are being achieved by a service. This approach is open to selective collection, again undermining data integrity and its value in informing service and system improvement. As the Government moves to support consumer choice and empowerment through consumer directed care, the outcomes reporting system must likewise be driven by consumer needs, priorities and assessment of what works, and what doesn't. Consumers are best placed to decide whether or not support meets their needs, and whether or not their goals have been met. The assessment process and the assessment tools must reflect this if we are to achieve robust data that supports meaningful comparison and learning in a benchmarking process.

The importance of appropriate access to data for research purposes

The Productivity Commission Issues Paper notes that limited access to data for research, including difficulties for researchers in obtaining administrative datasets for use as empirical evidence, is a recurring data-related theme across the Commission's previous work.¹⁷

There is currently no cure for dementia, and we lack effective therapies which significantly alter the disease trajectory. Research into prevention, early intervention, treatment, and system responses will help equip Australia to meet the massive challenges the sharp increase in dementia prevalence will present to our primary health care, hospital, residential aged care, disability, and community care systems. Sustained investment in dementia research is needed, encompassing risk reduction, care at all stages of the disease, and the search for effective curative treatments. The investment must support the translation of research into practice, to ensure that people with dementia and their families benefit through improved care and services. To complement this investment, Alzheimer's Australia recommends that researchers should have appropriate access to public data sets in cases where research and analysis of this data could promote better understanding and knowledge to support efforts to tackle dementia.

¹⁷ Productivity Commission (April 2016). *Issues paper: Data availability and use*; p.8.

CONCLUSION

Dementia is one of the major chronic diseases of this century. With the continued ageing of the population and the growing numbers of people with dementia, the care and support of people with dementia will be an increasingly significant issue for our community. The availability of high quality data on people with dementia, and their access to services and supports, will be critical in enabling appropriate policy and program development, and service planning; as well as in ensuring people with dementia and their carers have access to high quality information to assist them in decision-making.

We trust that the matters raised in this submission will be of assistance to the Productivity Commission in its consideration of issues relating to data availability and use.

ABOUT ALZHEIMER'S AUSTRALIA

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia is the second leading cause of death in Australia, and there is no cure.¹⁸

Alzheimer's Australia represents and supports the more than 353,800 Australians living with dementia, and the more than one million family members and others involved in their care¹⁹. Our organisation advocates for the needs of people living with all types of dementia, and for their families and carers; and provides support services, education, and information. We are committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.

¹⁸ Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013*: Cat no. 3303.0

¹⁹ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.